



MEMORANDUM

To: DRRC Members

From: Peter Thomas, Bobby Silverstein, and Joe Nahra

Date: February 18, 2022

Subject: DRRC 2021 Year in Review and Proposed Agenda for 2022

Executive Summary

We write to provide you with an update on the activities of the Disability and Rehabilitation Research Coalition (DRRC) in 2021. As we enter 2022, we want to provide a summary of the efforts made on behalf of the DRRC and its member organizations over the past twelve months, and to provide you with a forecast of issues that the coalition may engage in over the coming year.

We will review the initiatives outlined below and discuss our agenda for the upcoming year at the DRRC annual all-member meeting, to be held on **Tuesday, February 22 at 11:00am ET**. For more details or any questions, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com or Emily Goodwin at Emily.Goodwin@PowersLaw.com.

The DRRC's size and strength as a representative coalition of organizations concerned with the state of disability, independent living, and rehabilitation research is readily apparent in its active and productive portfolio of issues. Despite the continued uncertainty and upheaval of the COVID-19 pandemic, DRRC had a productive year in 2021, engaging with policymakers, federal agencies, and the rehabilitation research community to advance our preexisting priorities as well as key issues relating to the pandemic. The DRRC continues to see positive results in several of its initiatives, including:

- Advocacy regarding disability, independent living, and rehabilitation research relating to the COVID-19 pandemic, including data collection and targeted research for key populations.
- Providing feedback on research priorities and strategic planning relating to disability, independent living, and rehabilitation with key programs at the National Institutes of Health (NIH).
- Advocacy in support of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and its research mission in disability, independent living, and rehabilitation.
- Monitoring of and reporting on the Fiscal Year (FY) 2022 federal appropriations process and lobbying for increased funding of DRRC priorities.

- Continued national presence and activity through comment letters, direct agency engagement, and participation in national forums on issues related to disability, independent living, and rehabilitation research.

2021 Review: Initiatives and Engagement on Behalf of the DRRC

Throughout 2021, the DRRC engaged in a number of activities to advance rehabilitation, independent living, and disability research on multiple fronts. The following provides a summary of those initiatives and engagements conducted on behalf of the DRRC and its members.

I. Advocacy regarding disability, independent living, and rehabilitation research relating to the COVID-19 pandemic

Disability Status Data Collection

In the initial stages of the legislative and regulatory response to the pandemic, Congress and the Administration advanced specific efforts to coordinate and enhance the collection of data around COVID-19 infections, testing, diagnoses, and treatment. Initial legislation referenced the importance of disaggregating data by demographic characteristics, but often did not consistently identify disability status as a key characteristic to monitor. DRRC has continued our efforts to comprehensively include disability status data in demographic data collections relating to COVID-19 and beyond.

In February, the DRRC submitted a [package of comprehensive recommendations](#) to the leadership of the COVID-19 Health Equity Task Force (HETF), including recommendations regarding the collection of demographic data including disability status. These materials included a letter to Dr. Marcella Nunez-Smith, chair of the HETF regarding disability data collection relating to COVID-19 testing, diagnoses, treatment, and outcomes, as well as an appendix detailing some of the disparate burdens faced by people with disabilities during the pandemic. In March, representatives from the DRRC Steering Committee met with Dr. Nunez-Smith and staff from the HETF to discuss these recommendations. We continued our advocacy efforts with the HETF, including through public comments submitted live and [in writing](#) during the October meeting of the Task Force, and many of our recommendations relating to data were included in the Task Force's [final report](#) released in November.

In July, DRRC submitted a [written statement for the record](#) in response to the House Energy & Commerce (E&C) Committee's hearing on "Empowered by Data: Legislation to Advance Equity and Public Health." During the hearing, the E&C Committee considered more than a dozen public health bills focused around data collection; unfortunately, most of them did not explicitly include disability status as a required element in federal data collection. Our testimony urged the Committee to include disability as a mandatory component in all future legislation considered by Congress relating to health data.

Recommendations relating to disability data collection were also incorporated throughout DRRC comments on NIH and HHS strategic planning processes, detailed below.

Including Disability and Rehabilitation in the Federal Pandemic Research Agenda

The DRRC also continued our efforts to expand the impact of federal COVID-related research around people with disabilities, across the four themes we identified in 2020: ensuring inclusion of people with disabilities in existing COVID-19 research, disability-specific COVID-19 research, rehabilitation interventions for COVID-19 treatment and recovery, and the immediate impacts of the pandemic on people with disabilities.

Our recommendations to the COVID-19 Health Equity Task Force included our previous letter to NIH Director Francis Collins regarding support for federal research in these areas, as well as our detailed appendix of key research topics across each theme. As detailed below, we also advocated for significant increases in funding for federal research programs, particularly NIDILRR, to ensure sufficient capacity to conduct research in these areas.

Proposed Next Steps for 2022

The DRRC will continue working with Congress and the Biden Administration to advocate for enhanced disability, independent living, and rehabilitation research relating to the COVID-19 pandemic, including data collection, Long COVID, and targeted research for key populations. DRRC's activities relating to COVID will include:

1. Working with Congress and the Biden Administration to ensure that the federal response to the pandemic continues to include targeted research on the inequitable impact of COVID-19 and Long COVID on people with disabilities.
2. Ensuring that the COVID-19 research agenda includes examination of the "ripple effects" on access to services, health, and independent function not directly resulting from COVID-19 infection.
3. Ensuring that federal data collection efforts (related to COVID-19 and beyond) include disability status as a mandate category in all collections of demographic data.
4. Promoting disability considerations as research agencies continue to carry out their strategic plans and efforts regarding COVID-19 research.
5. Supporting federal research efforts into the impact of Long COVID on both people with preexisting disabilities and those with new long-term or permanent disability, as well as multidisciplinary rehabilitation for treatment of Long COVID symptoms and functional impairments.
6. Supporting research into the benefits and impacts of telehealth expansion during the COVID-19 public health emergency specifically for individuals with disabilities.

II. Advocacy before the National Institutes of Health

Meetings with NIH Leadership

Following the passage of bipartisan legislation to enhance and better coordinate medical rehabilitation research at NIH, the DRRC has been actively following and helping to shape the implementation of that legislation. During 2021, DRRC remained closely engaged with NIH staff, especially NCMRR leadership, regarding priorities for the disability and rehabilitation research community throughout the year. As noted above, the DRRC particularly focused on

ensuring that NIH leadership, as well as other key agency staff, understood the importance of federal investment into COVID-19 research on disability, independent living, and rehabilitation.

Additionally, representatives from the DRRC attended the virtual May and December 2021 meetings of the National Advisory Board on Medical Rehabilitation Research (NABMRR), the body that advises the directors of NIH, NICHD, and NCMRR on matters and policies relating to NCMRR's programs. The meetings included updates about NIH activities in the field of rehabilitation research, planned activities for the coming year, and updated numbers describing rehabilitation research funding across the various Institutes and Centers. In FY 2021, rehabilitation research across NIH topped **\$720 million**. We provided updates on these meetings to the DRRC membership on our monthly all-member calls and via email.

We also held several informal meetings and communications with NIH leaders to provide disability and rehabilitation community input on various strategic initiatives, including the proposed development of the Advanced Research Projects Agency for Health (ARPA-H). DRRC maintains a close working relationship with key NIH leaders including Dr. Alison Cernich, Deputy Director of NICHD, and Dr. Theresa Cruz, director of NCMRR.

Participation in NIH Strategic Planning Processes

In 2021, the DRRC took advantage of several opportunities to weigh in on the direction of NIH research on disability and rehabilitation by submitting formal comments on various strategic planning processes within NIH.

In March, DRRC submitted [comments](#) on the draft National Institute for Neurological Disorders and Stroke (NINDS) Strategic Plan for Fiscal Years (FY) 2021-2026. NINDS is the largest institutional funder of rehabilitation research at NIH. DRRC's comments focused on three themes within the draft plan, including expanding the NINDS biomarkers program to include consideration of outcome measures and social determinants of health to better understand disability and disease treatment; ensuring diversity, equity, inclusion, and accessibility (DEIA) within the NINDS workforce, NINDS training and mentorship programs, and among NINDS grantees including representation of people with disabilities; and incorporating quality of life as a key goal of NINDS research, including research into adaptive fitness and exercise, functional cognition, and community participation.

In April, DRRC submitted [comments](#) in response to NIH's Request for Information on Racial Equity, Diversity, and Inclusion in the Biomedical Research Workforce and Advancing Health Disparities and Health Equity Research. DRRC's comments urged NIH to recognize and include people with disabilities throughout agency-wide DEIA efforts, as explicitly stated in Executive Order 13895. In particular, the comments highlighted the intersectionality between race and disability; the need to address systemic barriers to disability participation in the scientific workforce, including through training programs and funding awards; and the importance of adopting community engagement requirements for research impacting people with disabilities.

Lastly, in November, DRRC submitted [comments](#) in response to the draft Department of Health and Human Services Strategic Plan for FY 2022-2026. These agency-wide comments reiterated

many of the key priorities for the Coalition, including the importance of standardized disability data collection, disability inclusion in federal workforce programs, and recognizing disability as a health disparity. DRRC also recommended new objectives be included in the Strategic Plan, including the identification of barriers to appropriate and affordable health care for people with disabilities and enhancing access to home- and community-based services for all individuals with disabilities.

Proposed Next Steps for 2022

DRRC should continue working with NIH leaders to promote rehabilitation science and follow up on visits from past years. Among those next steps, DRRC is proposing to conduct several related activities:

1. Follow up with those senior NIH leaders with whom DRRC has already engaged.
2. Meet with additional NIH leaders at Institutes and Centers relevant to the DRRC's mission, including the National Institute of Mental Health and the National Institute of Minority Health and Health Disparities to discuss the role of rehabilitation science at those ICs (likely via virtual meetings).
3. Continue to engage with new personnel at NCMRR to ensure a continued and strong relationship between the DRRC and the Center.
4. Meet with leaders at the NIH RECOVER initiative to maximize the impact of funds supporting research into Long COVID.
5. Participate in future public comment opportunities to weigh in on the direction of NIH-wide and Institute-specific strategic planning processes.
6. Engage with NIH to support diversity, equity, inclusion, and accessibility efforts within the Chief Office for Scientific Workforce Diversity (COSWD), NIH-wide, and across the scientific workforce including NIH employees and grantees.
7. Advocate for recognition of people with disabilities as a designated health disparity population within NIMHD and NIH-wide.

III. Advocacy in support of NIDILRR and its research mission

In May, President Biden appointed Dr. Anjali Forber-Pratt as the new director of NIDILRR, naming the first permanent director for the Institute in several years. DRRC focused on building a relationship with Dr. Forber-Pratt in her early tenure, and the coordinators held several offline conversations with her as well as an introductory call with the DRRC Steering Committee. This relationship has already led to open lines of communication, and Dr. Forber-Pratt has consistently notified the DRRC of important developments and opportunities as well as seeking our feedback as she develops her vision for NIDILRR.

In 2021, the DRRC continued its concerted efforts to increase the funding levels for NIDILRR. In order to capitalize on our success in 2020, we implemented an advocacy campaign targeted around NIDILRR for the Fiscal Year 2022 appropriations cycle. We continued our advocacy for a significant (\$10 million increase) for NIDILRR to address the need for applied research related to the pandemic and our key disability, independent living, and rehabilitation research themes. DRRC circulated letters to the key leaders on Appropriations Committees, including Sens. Patty Murray (D-WA), Roy Blunt (R-MO) [Senate letter available [here](#)] and Reps. Rosa DeLauro (D-

CT) and Tom Cole (R-OK) [House letter available [here](#)]. We also developed and submitted a specific funding request through Sen. Bob Casey (D-PA).

While Congress did not come to an agreement on an FY 2022 funding package in calendar year 2021, we did see significant progress on our appropriations priorities. In July, the House passed a full slate of appropriations bills, including a nearly \$12 million increase for NIDILRR – even more than our requested increase. The House bill included language directing funds to be used for increasing grants to NIDILRR’s model system centers, a \$100,000 increase for the Traumatic Brain Injury Model Systems National Data and Statistical Center, and \$2 million to increase the number of federally-funded Spinal Cord Injury Model System Centers. The Senate released a set of draft bills in October that were not marked up in committee (and thus do not include any input from Republican members) that included a \$6 million increase for NIDILRR.

We also conducted activities to support the Interagency Committee on Disability Research (ICDR), which is typically chaired by the NIDILRR Director as the designee of the Secretary of Health and Human Services. Dr. Forber-Pratt has taken this role as well, and we expect further dialogue between her and the DRRC to support her plans for reinvigorating the ICDR. In addition to our funding requests for NIDILRR, we sought specific report language highlighting the importance of ICDR, especially regarding disability data work in conjunction with the federal Equitable Data Working Group and requested \$2 million in dedicated funding for ICDR. The House-passed bill advanced in the summer included this language verbatim, though the Senate draft bill did not include any provisions specific to ICDR.

Proposed Next Steps for 2022

The DRRC should continue working with current NIDILRR leadership to promote applied disability, independent living, and rehabilitation research and advocate externally in support of NIDILRR and its research mission. In 2022, DRRC’s work will include:

1. Advocating for increased funding for NIDILRR’s operations in the FY 2022 and 2023 appropriations cycles.
2. Continuing to help facilitate the implementation of the 2018-2023 NIDILRR Long-Range Plan.
3. Working with NIDILRR leadership to provide input and help develop the next NIDILRR Long-Range Plan (for FY 2023-2029).
4. Meet with NIDILRR leadership and officials in the Administration for Community Living (ACL) to reaffirm commitment to disability, independent living, and rehabilitation research.
5. Working to more closely involve NIDILRR in CMS activities, especially regarding the role that NIDILRR’s data and disability expertise may play in improving the Medicare and Medicaid programs.

Specifically regarding ICDR, DRRC will advocate for an expanded recognition of the role of ICDR and enhanced collaboration on disability research across federal agencies by:

1. Advocating with ACL and the leadership of ICDR to promote the implementation of the government-wide strategic plan on disability, independent living, and rehabilitation research and encourage commitment to ICDR’s mission.

2. Advocating for federal government-wide efforts to expand self-declaration and self-identification for people with disabilities within the federal workforce and among those receiving federal funds.

IV. Fiscal Year 2022 Appropriations

In 2021, the DRRC advocated for report language and appropriate funding levels in the FY 2022 House and Senate Appropriations bills. Report language provides important non-binding guidance on Congressional intent for the provisions it describes, essentially outlining how Congress intends for federal agencies to spend appropriated funds. Several of our key priorities were included in both the House-passed appropriations bills and the Senate Appropriations Committee’s draft bills, including significant funding increases for NIDILRR, report language affirming the role of the ICDR, and language and funds supporting enhanced disability data collection at the Centers for Disease Control and Prevention.

As in previous years, the DRRC provided members with real-time updates on the progression of the FY 2022 appropriations process and disseminated materials detailing the decisions made in the President’s Budget and Congressional committees’ appropriations work. These included formal memos summarizing the major provisions of the budget and House-passed legislation, a searchable index and catalog of relevant report language, and our updated appropriations chart tracking funding for DRRC priority programs over time and displaying the proposed funding numbers, as well as the year-over-year increases from FY 2021 to FY 2022.

Our appropriations summaries can be found on the [DRRC website](#), available to DRRC members only. To access the appropriations page, enter the password “drrcaccess” when prompted.

Proposed Next Steps for 2022

In 2022, the DRRC anticipates continuing to advocate with the House and Senate Appropriations Committees for report language and funding requests in the omnibus FY 2022 and FY 2023 appropriations bills, and with the Biden Administration as appropriate, consistent with previous efforts. We will work with DRRC members to develop and prioritize appropriate requests to achieve the Coalition’s goals of advancing disability, independent living, and rehabilitation research.

Conclusion

With the ongoing impact of COVID-19 and a full slate of additional priorities in 2021, the DRRC carried out a high level of advocacy in a number of different areas regarding the enhancement of disability, independent living, and rehabilitation research at the federal level. We expect another busy year in 2022 and hope that the DRRC member organizations will continue to participate actively in the coalition to support this important work to benefit the populations we serve.

We encourage all DRRC members to join us (virtually) for the 2022 DRRC Annual Meeting, scheduled for Tuesday, February 22 from 11:00am – 1:00pm ET via Zoom. We will discuss our

work in 2021 and discuss how to build on our successes and establish new priorities in 2022. All current members should have received a calendar invite with the dial-in information; if you have any questions regarding the annual meeting, please contact Joe Nahra at Joseph.Nahra@PowersLaw.com or Emily Goodwin at Emily.Goodwin@PowersLaw.com.